

Original Article

Parent-reported health-related quality of life of children with cerebral palsy in Pakistan

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Abstract

Cerebral palsy (CP) affects movement, balance, and posture, leading to activity limitations, motor disability, and musculoskeletal problems. Health-related quality of life (HRQoL) assessment is critical in helping practitioners suggest interventions for children with CP. Therefore, this study was conducted to determine the parent-reported HRQoL among children with CP in Pakistan. Using a purposive sampling technique, 184 parents were interviewed face-to-face with the KIDSCREEN-52 questionnaire to assess their children's subjective health and well-being. The data were analyzed using descriptive statistics, chi-square, and Mann-Whitney tests. The HRQoL scores for physical activity and health were significantly lower for male children (median = 20.00) than for females (median = 10.00) ($p < 0.001$), which was also the lowest across all other dimensions of HRQoL. Male children scored higher than females in some domains, such as general mood and bullying, while female children scored higher in domains such as free time and friends, but these differences were not statistically significant ($p > 0.05$). The overall HRQoL score was low for both male (median = 43.84) and female (median = 42.26) children. However, there was no significant difference in the proportion of children with low and medium HRQoL scores based on gender. This study concluded that physical activities and health were the poorest dimensions of HRQoL. The results help better understand children's lived experiences as perceived by their parents, highlighting various aspects of health that could be optimized to enhance the overall quality of life. Our findings highlight the need for targeted interventions to improve the HRQoL of children with CP, especially regarding physical activity and health.

Keywords

Quality of life; Parents; Cerebral palsy; Children with developmental disabilities; Self-report

1. Introduction

Healthy children enjoy the early years of their lives compared to children with disabilities who face difficulties and remain dependent on medical care, requiring more human attention to improve their quality of life [1]. The World Health Organization (WHO) defines quality of life as a multidimensional concept incorporating the individual's subjective perception of their position in life [2]. Therefore, health-related quality of life (HRQoL) is an important indicator that helps understand the effects of illness and disability on the quality of life of children. Furthermore, it does not affect the living standard of ill or disabled children alone but of whole families, especially their primary caregivers, i.e., parents [3].

Cerebral palsy (CP) is a common disorder prevalent among infants that can affect the body's ability to move or maintain balance or posture, leading to activity limitation [4]. Moreover, motor disability among CP children can result in muscle weakness along

with abnormal perception, communication, sensation, and cognition, leading to motor impairment or musculoskeletal problems [5]. CP results in poor growth of the children compared to normal and healthy children; however, the improvement and precision in motor activities with time is slow compared to normal healthy children. In addition, CP children may experience problems such as learning disabilities, epilepsy, and mental retardation associated with a physical disability, depending on the damaged brain area [6, 7].

Almost 2.5 children per 1000 live births are likely to experience severe motor impairment with CP in the early stages of their life [8]. However, the prevalence of CP is higher among preterm babies, with a higher incidence among male children than female children [9]. The incidence rate of comorbidities among children with CP includes an IQ score of less than 50 among 31% of children, seizures in 21%, and nonambulatory among 20% of children [10]. In Pakistan, CP is the most common disability in the early stages of life in different districts of Sindh, affecting more than 30% of children [11].

HRQoL is an important health-related outcome measure with clinical utility in helping practitioners suggest rehabilitation interventions among children with CP [12]. Generally, satisfaction with life depends upon personality traits, events in life, moods, and a person's cognitive abilities. Therefore, assessing HRQoL is also important because it is linked to an individual's satisfaction with life and happiness [13]. Furthermore, it plays a critical role in an individual's daily life and functioning because it is considered a major personal development goal; hence, evaluating HRQoL holds scientific importance, especially among CP children [14].

Several challenges can significantly affect parents' lives while caring for their children with CP, which may alter their family functioning. The level of care is directly related to disease severity, mobility disorders, delayed development, and medical and rehabilitation interventions. The health status of children with CP can be improved with critical medical care, but raising these children is equally challenging for parents, which includes managing child health problems effectively, understanding their behavioral difficulties, and learning requirements to act as a friendly guardian [13, 15].

The prolonged care of children with chronic health conditions is associated with feelings of helplessness, anger, sadness, and fear among caregivers, affecting their mental health, capabilities, and functioning [16, 17]. Hence, healthcare professionals must provide psychological support to children with CP and their families, together with medical treatment [18]. Furthermore, a better home environment increases the likelihood of optimizing the development of children with CP [16]. Therefore, the HRQoL of children with CP cannot be overlooked while making health interventions by healthcare professionals. Hence, this study was conducted to determine the parent-reported HRQoL of children with CP in Lahore, Pakistan.

2. Material and methods

2.1. Study design

This is a cross-sectional study.

2.2. Ethics approval

This study was approved by the Ethics Review Committee of the affiliated college of the Government College University Faisalabad (No. HCHS/2022/ERC/10). The data were collected between March and July 2022.

2.3. Study setting

This study was conducted at three public and private healthcare facilities in Lahore, i.e., the Pakistan Society for the Rehabilitation of the Differently Abled Hospital, Al-Shafi Hospital, and Children Hospital.

2.4. Participant recruitment

Parents for this study were recruited with children with CP aged 8 and 12 without comorbidities who visited the targeted healthcare facilities [8]. Children with CP had documented motor impairment, such as muscle weakness, spasticity, or involuntary movements. However, parents who could not understand local languages and did not provide written informed consent were excluded from the study.

2.5. Sample size and sampling technique

The minimum sample size calculated was 184 using the Raosoft calculator by keeping a 5% margin of error, a 95% confidence interval, and a response distribution of 86 [19]. The parents were included in this study by employing a nonprobability purposive sampling technique.

2.6. Study instrument development

We used a reliable and validated KIDSCREEN-52 questionnaire to assess children's subjective health and well-being in addition to a few open-ended questions used in a previously conducted study [6].

2.7. Data collection

The principal investigator interviewed the parents with CP at the targeted facilities face-to-face, which lasted between 15 and 20 minutes.

2.8. Study measures

The study instrument collected information related to sociodemographics. Moreover, the KIDSCREEN-52 questionnaire collected information regarding physical activities and health, feelings, general mood, about yourself, free time, family and home life, money matters, friends, school and learning, and bullying. The responses were collected using a Likert scale ranging from 'poor' to 'excellent', 'not at all' to 'extremely', and 'never' to 'always' with assigned scores ranging from 1 to 5. However, the scores were assigned in reverse from 5 to 1 to the abovementioned Likert scales for the first element of 'physical activities and health', all seven elements of 'general mood', the third, fourth, and fifth elements of 'about yourself', and the first, second and third elements of 'bullying' [20].

The scores for each of the ten domains of the KIDSCREEN-52 questionnaire were calculated by summing the scores of all the items in each domain, including any reverse-scored items [21]. These scores were then transformed into a scale ranging from 0 to 100 using the formula 1:

$$\text{Domain score} = (\text{score} - \text{minimum possible score}) / (\text{maximum possible score} - \text{minimum possible score}) \times 100 \quad (1)$$

Finally, the average score of all ten domains was calculated by adding the domain scores and dividing by the total number of domains to obtain the overall KIDSCREEN-52 score. Higher values indicated a higher HRQoL.

The overall KIDSCREEN-52 score was interpreted based on predetermined criteria: scores ranging from 0 to 25 were considered very low, scores from 25 to 50 were considered low, scores from 50 to 75 were considered high, and scores from 75 to 100 were considered very high [22]. In addition, for each domain score, scores below 33.3 were con-

sidered low, scores between 33.3 and 66.6 were considered medium, and scores above 66.6 were considered high.

2.9. Statistical analysis

The descriptive statistics were calculated using frequencies, percentages, means, ranges, and standard deviations (SDs). Moreover, the median and interquartile range (IQR) for each domain of the KIDSCREEN-52 questionnaire were calculated using the converted values of the sum of scores obtained from each element of the individual domain. In addition, the Chi-square test and Mann-Whitney U test were used to achieve the study's objectives using Statistical Package for Social Sciences (SPSS) [version 26.00 (IBM Corp., Armonk, NY, USA)].

3. Results

Table 1 shows that the children's average age was 9.43 ± 1.45 years. Moreover, the average monthly household income was Pakistani Rupees (PKR) $51,201.09 \pm 15,755.57$. Table 2 shows the other sociodemographic attributes of the study participants. Most children suffering from CP were males (55.43%) compared to their female counterparts (44.57%) and were mostly accompanied by their mothers (72.28%) rather than their fathers (27.72%) as attendants. In addition, most of the families were residents of urban areas (69.02%) rather than those living in rural areas (30.98%).

Table 1. Sociodemographic information of study participants (n = 184)

Variable	Mean \pm SD	Range	
		Min.	Max.
Age of child (in years)	9.43 ± 1.45	8.00	13.00
Mother's age (in years)	37.52 ± 4.98	29.00	49.00
Father's age (in years)	40.30 ± 5.24	32.00	50.00
Monthly household income (in PKR)	$51,201.09 \pm 15,755.57$	23,000.00	95,000.00

Table 2. Demographics data of study participants (n = 184)

Demographics		N	%
Gender of the child	Male	102	55.43
	Female	82	44.57
Attendant relationship with the child	Mother	133	72.28
	Father	51	27.72
Locality of family	Urban	127	69.02
	Rural	57	30.98
Mother's occupation	Self-employed	12	6.52
	Employed	25	13.59
	Housewife	147	79.89
Father's occupation	Self-employed	69	37.50
	Employed	105	57.07
	Unemployed	10	5.34

Table 3 presents HRQoL scores of different dimensions based on the gender of children. The average scores for physical activity and health were significantly lower for male children (median = 20.00) than for female children (median = 10.00) ($p < 0.001$), which was also the lowest across all other dimensions of HRQoL. Male children scored higher than females in some domains, such as general mood and bullying, while female

children scored higher in domains such as free time and friends, but these differences were not statistically significant ($p > 0.05$). Overall, the HRQoL score was low for both male (median = 43.84) and female (median = 42.26) children. However, there was no significant difference in the proportion of children with low and medium HRQoL scores based on gender.

Table 3. Parent-reported HRQoL scores by gender of the children (n = 184)

Description	Male Children		Female Children		p value *,**
	Median (IQR)	Score Interpretation	Median (IQR)	Score Interpretation	
Physical activities and health	20.00 (10.00 – 40.00)	Very Low	10.00 (00.00 – 20.00)	Very Low	0.001 ***
Feelings	35.41 (20.83 – 45.83)	Low	33.33 (25.00 – 41.67)	Low	0.802
General mood	55.36 (35.71 – 64.29)	High	42.86 (35.71 – 60.71)	Low	0.435
About yourself	50.00 (45.00 – 55.00)	High	50.00 (45.00 – 55.00)	High	0.994
Free time	45.00 (30.00 – 65.00)	Low	55.00 (35.00 – 65.00)	High	0.304
Family and home life	58.33 (58.33 – 75.00)	High	66.67 (58.33 – 75.00)	High	0.501
Money matters	33.33 (25.00 – 50.00)	Low	41.67 (25.00 – 41.67)	Low	0.649
Friends	43.75 (37.50 – 62.50)	Low	50.00 (37.50 – 62.50)	High	0.329
School and learning	33.33 (20.83 – 41.67)	Low	33.33 (25.00 – 37.50)	Low	0.923
Bullying	58.33 (33.33 – 75.00)	High	41.67 (33.33 – 66.67)	Low	0.235
Overall HRQoL score	43.84 (36.25 – 47.92)	Low	42.26 (40.00 – 45.83)	Low	0.371
Proportion of Parent-Reported HRQoL of CP Children by Gender					
Low, N (%)	12 (11.76)	-	12 (14.63)	-	0.360
Medium, N (%)	90 (88.24)	-	70 (85.37)	-	
High, N (%)	0 (0.00)	-	0 (0.00)	-	

* Physical activities and health, feelings, general mood, about yourself, free time, family and home life, money matters, friends, school and learning, bullying, and overall HRQoL score are compared using the Mann-Whitney Test. ** Proportion of parent-reported HRQoL of CP children by gender is compared using the chi-square test. *** Significant value ($p < 0.05$).

4. Discussion

The results of our study showed that most children suffering from CP were males compared to their female counterparts and were accompanied mainly by their mothers rather than their fathers as attendants. In addition, most families were residents of urban areas rather than those living in rural areas. The HRQoL scores for physical activity and health were significantly lower for male children than for female children and were also the lowest across all other dimensions of HRQoL. Male children scored higher than females in some domains, such as general mood and bullying, while female children scored higher in domains such as free time and friends, but these differences were not statistically significant. Overall, the HRQoL score was low for both male and female children. However, there was no significant difference in the proportion of children with low and medium HRQoL scores based on gender.

Our results are consistent with a study that assessed HRQoL in children with CP [23]. The study found that 30% of the sample had severely affected HRQoL, 37% had moderately affected HRQoL, and 24% had mildly affected HRQoL. Furthermore, the study reported that mobility, physical independence, and social aspects of life were more significantly affected than the economic and school dimensions [23]. Another study examining HRQoL in male and female children with CP reported reduced HRQoL, with lower physical and parent domain scores than mental abilities [24]. Our findings are consistent with an Iranian study that showed a significant association between gross motor function, participation, and physical health [25]. Conversely, research conducted in India indicated

that gender is not correlated with the nature of CP or epilepsy in children [26]. Our study results are supported by a systematic review that showed that CP children in low- and middle-income countries tend to have lower HRQoL scores across all instrument dimensions than age-matched controls ($p < 0.003$) [27]. Moreover, a study that assessed HRQoL in youth with CP reported that 57% rated their health status as excellent or very good, with a mean health utility score of 0.30, which supports our findings [28].

Cerebral palsy is a lifelong disease, and multiple factors contribute to determining the quality of life of a patient, primarily including quality of care and severity of the disease. A Nigerian study used the child health questionnaire parent form (CHQ-PF28) and reported that most respondents scored very low (69.5%), i.e., level 1, as per the Gross Motor Function Classification System. In addition, HRQoL among children with cerebral palsy was negatively affected by the duration and severity of the disease (confidence interval (CI) = 95%) [29]. A study on male and female Slovenian children highlighted that children had better HRQoL than caregivers and adults, with better social inclusion and independence [30]. The study conducted in Korea highlighted that the mothers of the affected children had lower HRQoL. Most mothers felt alone and found it challenging to communicate and make friends, ultimately affecting their quality of life [31]. A study conducted in Australia compared the quality of life of CP children and habitual physical activity concerning their ambulatory status. The study's results highlighted that ambulant patients had a better quality of life than nonambulant patients in physical health, participation, and feelings about functioning. Furthermore, habitual physical activity was not associated with parent-reported quality of life [32]. Similarly, a study reported parents' perceptions that male children with CP have compromised HRQoL compared to female children [23]. In addition to other factors, the healthcare system and professionals undeniably have an essential role in supporting caregivers and affected children [28].

This study contributes to the scientific literature focusing on the Pakistani perspective, which marks the potential strength of the study. However, the study was performed on a limited number of participants that only focused on the patient-reported HRQoL outcome and did not consider the other aspects, which can be attributed to the study's weakness.

5. Conclusions

Our study concluded that physical activities and health were the poorest dimensions of HRQoL. Moreover, our results help better understand the lived experiences of children, as perceived by their parents, and suggest various aspects of health that could be influenced to optimize their overall quality of life. Our findings highlight the need for targeted interventions to improve the HRQoL of children with CP, especially regarding physical activity and health.

Author contributions: Conceptualization, SS and HR; methodology, SS and HR; software, SS; validation, HR; formal analysis, SS; investigation, HR; resources, SS and HR; data curation, SS; writing—original draft preparation, SS and HR; writing—review and editing, SS and HR; visualization, SS and HR; project administration, SS and HR. Both authors have read and agreed to the published version of the manuscript.

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Ethics statement: This study was approved by the Ethics Review Committee of the affiliated college of the Government College University Faisalabad (No. HCHS/2022/ERC/10).

Consent to participate: Informed consent was obtained from all individual participants included in the study.

Data availability: The data supporting this study's findings are available from the corresponding author, Sana, upon reasonable request.

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Conflicts of interest: The authors declare no conflicts of interest.

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